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Feasibility and acceptability evaluation of the PRIDE (Promoting Independence in Dementia) intervention for living well with dementia

Running Title: PRIDE Feasibility Study

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ABSTRACT

Objectives: Post-diagnostic psychosocial interventions could play an important role in supporting people with mild dementia remain independent. The PRIDE intervention was developed to address this.

Method: The mixed methods non-randomised, pre-post feasibility study occurred across England. Facilitators were recruited from the voluntary sector and memory services. Participants and their supporters took part in the 3-session intervention. Outcome measures were collected at baseline and follow-up. To evaluate acceptability, focus groups and interviews were conducted with a sub-sample of participants and facilitators.

Results: Contextual challenges to delivery including national research governance changes, affecting recruitment of study sites. Thirty-four dyads consented, with 14 facilitators providing the intervention. Dyads took part in at least two sessions (79%), and 73% in all three. Outcome measures were completed by 79% without difficulty, with minimal missing data. No significant changes were found on pre and post assessments. Post-hoc analysis found moderate effect size improvements for self-management (*SMAS* instrument) in people with dementia (d=0 .41) and quality of life (*EQ5D* measure) in carers (d=0.40). Qualitative data indicated that dyads found PRIDE acceptable, as did intervention facilitators.

Conclusions: The 3-session intervention was well accepted by participant-dyads and intervention facilitators. A randomised controlled trial of PRIDE would need to carefully consider recruitment potential across geographically varied settings, and site-stratification

according to knowledge of contextual factors, such as the diversity of post-diagnostic services across the country. Letting sites themselves be responsible for identifying suitable intervention facilitators was successful. The self-report measures showed potential to be included in the main trial.

Keywords: Dementia, Psychosocial Intervention, Research Design and Methodology, Community Care

INTRODUCTION

The EU Joint Programme for Neurodegenerative Disease Research and the UK government have highlighted the need for the development of high quality specialist services, in particular psychosocial interventions, to support people with dementia (DOH, 2016). People with dementia may reduce their activities due to perceived stigma, neurodegenerative decline, loss of autonomy and self-confidence (Birt et al., 2017; Lion et al., 2019). Furthermore, family and friends may also inadvertently contribute to a reduced sense of self-determination (Sterin,2002). Given the risk of 'prescribed disengagement' at the time of diagnosis (Low et al., 2018), counteracting this soon after diagnosis may facilitate better adjustment and ongoing management of dementia (Burgener et al., 2009). This in turn may enhance independence and social inclusion and delay residential home placement (Clarke et al., 2103).

The overall objective of the Promoting Independence in Dementia (PRIDE) programme was to develop an intervention to improve independence. This intervention was built on a framework of research, such as epidemiological and qualitative data, and PPI involvement (Csipke et al., 2018; Yates et al., 2019). PRIDE included work from the English Longitudinal Study of Aging (ELSA; Steptoe et al., 2013) cohort study which found that loneliness was linked to cognitive decline, although social isolation in itself was not (Rafnsson et al., 2017), and those with close social networks had a reduced risk of cognitive decline (Khondoker et al., 2017). Furthermore, we found that physical activity was associated with both a lower risk and progression of dementia (d'Orsi et al., 2017; Soni et al., 2017; Stock et al., 2015). Our critique of literature about social participation highlighted challenges associated with memory loss, social relationships and social structures in enabling people with dementia to remain

independent (Birt et al., 2019). Unlike some similar interventions, stakeholders (persons with dementia, carers and older people) contributed to shaping the PRIDE intervention (Yates et al., 2019).

The Medical Research Council recommends that uncertainties associated with conducting a large- scale study can be addressed in feasibility work (Craig et al., 2008). Our aims were therefore to examine the feasibility of the PRIDE intervention by investigating: recruitment and retention rates across sites; engagement of intervention facilitators and participants; the acceptability of the PRIDE intervention; and choice of what has the best potential as an outcome measure for a future large- scale study.

METHOD

Design

This is a mixed methods feasibility study of the PRIDE intervention (see protocol; Csipke et al., 2018). Outcome measures were collected at baseline and post-intervention, to test feasibility of use with participants and to inform the design and methods for a future large-scale study. A sub-sample of participants and intervention facilitators took part in interviews/focus groups following the intervention, to examine the acceptability, engagement and delivery of PRIDE.

Participants

Participants were adults (18+) who were able to read and communicate verbally in English and had the capacity to give informed consent in accordance with the Mental Capacity Act (DCA, 2005).

Persons with dementia were community dwelling, with a dementia-diagnosis and with mild dementia, as defined by 0.5-1 on the Clinical Dementia Rating (CDR) Scale (Morris, 1993). They were expected to have a supporter (family member or friend) willing to participate with them. Supporters were included since, although the intervention focussed on those with dementia, the influence of social factors (such as relationships with family or friends) influence the 'dynamic balance between opportunities and limitations in dementia' (Vernooij-dasssen, Moniz-Cook & Jeon, 2018). These factors underpin many of the concepts of PRIDE such as decision-making, communication and participation, and are also key to delivery of psychosocial intervention in dementia care. Instead of the term 'carer', which implies 'dependence', the term 'supporter' was used throughout, since it denotes mutuality and reciprocity within a relationship.

Supporters were eligible if they were in regular unpaid contact with the person with dementia (minimum three hours a week).

Intervention Facilitators were either voluntary sector staff working as 'Dementia Advisor Workers (DAWs)' who provided information, advice and support, alongside or within memory clinics, or health and research staff working with memory services.

Sample size and sites

Sample size calculations were not made. Instead, we planned to use sites that were geographically varied to explore recruitment across diverse settings, in order to replicate the diversity of provision and organisation of services across the country. We aimed to recruit up to five sites across England, with approximately ten dyads at each site. This would provide sufficient data to evaluate recruitment and retention rates, time required to recruit dyads, whether the participants and facilitators found the intervention to be acceptable and to test outcome measures. Sites were eligible if they had local researchers within Research and Development departments, to undertake the baseline and follow-up measures; could provide a supervising clinician acting as a principal investigator; and had access to dementia facilitators to deliver the intervention. We provided site-based researchers with training in screening, measure completion and all study procedures.

Procedures

Recruitment was through NHS memory services, Join Dementia Research (a national register of people interested in taking part in dementia research), and voluntary sector organisations. Potential participants were approached by clinic or voluntary sector staff and given study information. If they agreed to participate, researchers arranged to obtain written informed consent and completed the *Clinical Dementia Rating (CDR; Morris, 1993*) to check that participants had a score of 0.5-1 (mild dementia), following which baseline measures were completed. Dyads were linked with local intervention facilitators who would then meet with them on three occasions, approximately four weeks apart. After the final session, follow-up outcome measures were completed, within four weeks of the final session.

Referral sources, along with reasons for ineligibility, and retention rates were recorded. Additional support such as telephone calls or requests for extra sessions were recorded. Additional support required by research sites and intervention facilitators, such as site visits and further training were also recorded.

Ethics

The study was approved by the East Midlands Nottingham 1 Research Ethics Committee (16/EM/0044). Participants were fully informed of potential risks and benefits and that they would be free to withdraw at any time without affecting their care. Participants with mild dementia were expected to have capacity to provide consent for themselves (Csipke et al., 2018). In addition to providing consent at the start of the study, researchers were aware of the need to regularly check participants' understanding of the research process. The study also obtained Health Research Authority (HRA; https://www.hra.nhs.uk/approvals-amendments/) approval via the sponsoring university for governance and legal compliance required for NHS sites to carry out studies. Safety procedures for researchers in the UK followed standard guidelines. Reporting procedures for serious adverse events (SAE's), were in place at all sites.

The PRIDE intervention

A facilitator delivers the intervention in three, 60-90 minute sessions. The intervention aims to equip the person to participate in activities, build on communication skills and enable them to continue making choices during the course of their dementia. In between sessions, the person is encouraged to engage in activities to support their independence, social inclusion,

and engagement in the community. A paper-based workbook with space for written records supports usage in and between sessions (Yates et al., 2019).

Acceptability of intervention and study procedures - qualitative data

A convenience sample was used to: (1) explore if participants found the intervention/study procedures suitable and feasible; (2) obtain their views on taking part; and (3) obtain views of the intervention facilitators. Focus groups and in-depth interviews were used to collect this data, since they provide an opportunity for new perspectives on experiences to develop as participants discuss and where relevant challenge each other's views (Jenson and Laurie, 2016). For interview topic guides see Tables 1 and 2.

-Insert Tables 1 & 2 here-

Feasibility and Acceptability of Outcome measurement - quantitative data

Researchers read instrument questions out to participants to ensure consistency and promote inclusiveness for those who found reading text difficult. During this time, supporters were asked to complete self-report questionnaires. All measures have demonstrated good psychometric properties and have been used in populations with dementia. However, since some instruments have not been used in intervention studies, the degree of sensitivity to change in terms of reporting treatment effects is unknown. We therefore selected a number of measures that were aligned to the PRIDE intervention concepts and goals, in order to inform on what might be suitable in a future large-scale study.

For people with dementia the included measures reflected the core of the intervention. These were: Self-management Ability Scale (the *SMAS-30; Schuurman et al., 2005*); independence (the *CASP-19; Hyde et al., 2003*); engagement and independence (the *Engagement and Independence in Dementia Questionnaire – EID; Stoner et al., 2017)*; the Impact on Participation and Autonomy scale (*IPA; Hammar et al., 2014*) measuring self-determination and participation; hope and resilience (the *Positive Psychology Outcome Measure - PPOM; Stoner et al., 2017*); and loneliness/social support (the *ELSA three-item social support questions* taken from: the *revised version* of the *UCLA Loneliness Scale; Hughes et al., 2014*). Measures also included activities of daily living (*The Bristol Activities of Daily Living Scale – BADLS; Bucks et al., 1996*; rated by the supporter), cognitive function (*Standardized Mini-Mental State Examination SMMSE; Vertesti et al., 2001;* the *Hopkins Verbal Fluency and Learning Test*; *Brandt, 1991*); functional mobility (*Timed Up and Go test - TUG; Podsiadlo and Richardson, 1991*); quality of life (*Dementia Quality of Life measure – DEMQOL; Smith et al., 2005*; *Health-related quality of life - EQ-5D; Euroqol Group, 1990*); and economics in relation to well-being (the *Icecap capability measure for Older people* (*ICECAP-O; Coast et al., 2008)*.

Supporters completed self-report measures as follows: the quality of life *EQ-5D (Euroquol Group, 1990)* and the economic well-being measure *ICECAP-O (Coast et al., 2008).*

The *Client Services Receipt Inventory* (*CSRI*; -Morris, 1993) for measuring service costs was also used, but only to examine its acceptability by participants, so no analysis was planned using this instrument.

Participants and intervention facilitators were asked to complete three fidelity checklists, one each after the three sessions, to examine adherence to the intervention (i.e. whether the intervention was delivered as planned and whether the participant engaged with the intervention). Components of the checklists were standardised to reflect the intervention (i.e. Session 1 = 22 components; session 2 = 18 components; session 3 =12 components). Interventionist and participant (i.e. 'your experience') checklists contained the same key components (see Walton et al 2020).

Analyses

Quantitative

Researchers completed measures with participants, and any difficulties were recorded. The analysis steps were: examine missing data for patterns of non-completion; conduct multiple imputations with a linear regression for scale variables at baseline and post intervention to impute missing variables; use basic pre-post t-tests for normally distributed data or non-parametric Wilcoxon rank tests for other data; carry out post hoc analyses, when differences in means warrant this.

Qualitative

Qualitative data from focus groups and interviews with participants and intervention facilitators were audio recorded and transcribed, using framework analysis for evaluation of applied interventions (Srivastava and Thompson, 2009). The analytical steps were: familiarisation with the data, generating initial codes which reflect the research questions in topic guides, producing a thematic framework, index charting and mapping of data which

enables reflection on differences and similarities in experiences of the stakeholder and also interpretation and presentation of themes; explore findings to see if there were differences in the experiences of people with dementia, supporters or intervention facilitators, to add further understandings of the intervention in the real world.

RESULTS

Site Recruitment and Set up

Six NHS Foundation Trusts with memory services expressed an interest in participating in the study. Two sites withdrew following delays due to internal reorganisation within their services as they were unable to identify both researchers and intervention facilitators within the timeframe. All participating sites were predominantly urban. Each site was provided with a site set-up visit lasting 2-3 hours, which included training and information covering participant identification/screening/consenting, and measure administration. Sites were also given instruction in study procedures such as communications with the research team, data collection and entry, and documentation and site files.

Obstacles to implementing the study

The final sample was smaller than initially planned due to restructuring of national NHS research governance processes, and associated delays of 10 months to set-up of the study, which also contributed to the withdrawal of the two sites from the study. The rate of recruitment was also slow, taking 10 months to recruit 34 dyads. A third obstacle related to changes in the facilitator workforce where availability of DAWs fluctuated on an annual basis according to local commissioning arrangements. For example: the aforementioned delays in

national governance procedures resulted in intervention facilitators from the voluntary sector who had been willing to engage in intervention delivery, now no longer in post 10 months later; legal agreement with one of voluntary organisations was very time consuming with head office delays impacting on availability of staff to deliver the intervention; where DAWs were available and engaged, the NHS site withdrew from the study; and many DAWs were unable to add to their workload to deliver this intervention even when remuneration for time and training was offered. We overcame obstacles to engaging intervention facilitators by working with NHS research departments at each site and their clinical service managers to nominate intervention deliverers from their memory services.

Dyad recruitment

One hundred and fifteen potential participants were identified across the four participating sites. These were from: the JDR register (n= 61), the voluntary sector (n=5), participants from other studies (n=23); memory clinics referral (n= 25) and psychiatrist referral (n=1). Of these, 23 (20%) were uncontactable, and 23 (20%) were out of the study-site catchment areas, seven (6%) were not clinically eligible, 14 (12%) were not eligible for other reasons. Of the 48 who were eligible, 14 (29%) declined to take part, leaving 34 dyads recruited to the study. Recruitment ended at ten months, to allow for time for intervention delivery and completion of follow-up.

The mean age of participants was 77.67 (SD= 9.07) and 23 (67%) were men. Thirty-three (97%) were White British and one (3%) was of Asian ethnicity. Half of participants were diagnosed with Alzheimer's disease, six (18%) had mixed dementia, four (12%) vascular dementias, one (3%) with Lewy body dementia and the remaining six (16%) had an

unspecified dementia-diagnosis. Twenty- seven (79%) supporters were female. The average age of all supporters was 69.18 (SD=11.89).

The flowchart of study recruitment and retention is shown in Figure 1.

- Insert Figure 1 here –

Four participant/supporter dyads (4 males with dementia; 4 spousal supporters) were recruited to a focus group, at two sites and three intervention facilitators (females) also agreed to take part in focus groups. Individual telephone interviews were conducted at two sites with two participants (males) and two supporters (females) at each site.

Facilitator Recruitment and Training

Twenty-six health professionals from voluntary organisations and NHS teams registered for and completed the training programme, with sessions delivered at each site. Training was presented by members of the research team who had been involved in the development of the intervention and all had previous experience of running training programmes. Training lasted one day, consisting of lectures, interactive groups activities, role-play and reflection. Managers and staff not planning to deliver the intervention were invited to attend to: enhance support during the study; maximize interaction opportunities between different teams and; build relationships during the training itself. Eleven (43%) were voluntary sector staff, seven (27%) clinical researchers, four (15%) dementia nurses, and four (15%) allied health professionals. Fourteen (54%) of those who took part delivered the PRIDE intervention. The remaining 12 trainees (who did not deliver the intervention due to high workloads), were managers attending the training for their own information, or were staff who were shortly to leave their organisations.

Intervention Delivery and Uptake

Of 34 consenting dyads, 33 took part in the first session. Subsequently, seven withdrew; one due to ill health, one due to the supporter's ill health, one due to facilitator drop out, and four gave no reason. Twenty-six (79%) took part in two sessions, and 24 (73%) in all three sessions, none requested an extra session. Five took up the offer of telephone contact, with eight calls taking place. Calls took 5-15 minutes and involved updates from the participants about their activities.

One site reported three SAE's (hospital treatment for a medical condition unrelated to PRIDE).

Site and intervention facilitators were offered support from the study team as required, and two newsletters updating on progress were sent to all sites. The study team offered additional site visits if required, but only one site took up this offer. All sites had on-going questions about procedural issues, which were resolved via telephone or email.

Measure Performance

All consenting participant-dyads (n=34) completed baseline measures and 27 (79%) completed the follow-up.

Outcome Measures

Measures were completed without significant difficulty, despite the numerous instruments used, including the lengthy CSRI. Data collection took approximately 1-2 hours, and all were completed in a single session. There were particular challenges associated with the *TUG* measure of gait, which involved walking across a room in straight line: some participants' homes did not have sufficient trip-free space – although solutions were found in all cases. None of the measures caused distress.

There were no measures or specific items with enough missing data to warrant concern, and overall less than 2% of data was missing, over both time points, for both participants and supporters.

Exploratory t-tests (baseline versus follow up) were carried out as per study protocol (Tables 3 and 4). No significant differences were found, although the *SMMSE* approached significance at p=0.05. Post hoc analysis found that the *SMAS* had a moderate effect size (d) of 0.41 indicating that self-management scores for people with dementia improved. In addition, the EQ5D for supporters indicated a moderate effect size (d = 0.40) indicating that general quality of life scores improved.

Based on post hoc exploration (effect sizes; Cohen's D), further analysis of *SMAS* scores was carried out taking into consideration engagement (from fidelity checklist) with the intervention. In this analysis, only scores on enactment (doing what was planned in the session) were used. Where fidelity checklist scores were available these were converted into categories of ≤75% or 76-100% enactment. *SMAS* means were calculated for the two categories where fidelity checklists scored were available, at baseline and follow up. Those with higher engagement scores demonstrated better self-management abilities at baseline,

which remained true at follow up (no change in scores). The group with lower engagement also had the lower baseline self-management scores, but by the end of the intervention at follow up these matched the first group (Table 5).

-Tables 3, 4 & 5 here-

Qualitative findings

Three themes emerged from the qualitative analysis: understanding the ethos of the PRIDE intervention; relationships within the PRIDE intervention and the relevance of the PRIDE intervention.

Understanding the PRIDE study ethos

Participants were able to articulate the ethos of the PRIDE intervention as being that of enabling people with dementia to maintain some independence. The sense of hope instilled through the intervention was captured by a facilitator who stated:

> *It's for maintaining independence, isn't it, and it's ensuring that people are constantly putting things in place to make sure that they live happy, independent and active lives… to stay in control of their lives (Facilitator 2)*

People with dementia and their supporters spoke of the confidence they gained through being part of the PRIDE intervention.

> *thought it was very good. [filling in manual] It gives everybody, erm… can't think of the word… researchers and everybody knows what I'm doing and how I'm thinking. I thought that was good, anyway. (Person with dementia 3)*

Facilitators helped participants engage, for example where a person with dementia found it difficult to communicate, use of a singing video helped her relax and the facilitator noted:

> *she held my hand and said thank you, she was understanding that we were adapting it not to make her feel threatened or anything like that but to do it to the way that she enjoyed … so that she could still take part in everything (Facilitator 3)*

Relationships within the PRIDE intervention

Facilitators worked face-to-face through the manual and activities with the participants and helped set priorities and action plans. All people spoke of this personal contact as important:

> *The best benefit we got was actually talking to the people that came out. I think that made a lot of difference, person to person. (Supporter 2)*

Both facilitators and supporters acknowledged the essential role the supporter played in encouraging the person with dementia to engage in the intervention. This might have been helping the person with dementia engage in intervention plans in practical ways such as getting equipment and keeping action plans up to date.

> *I think he was definitely prompting her to do the knitting and he went out to the shops and bought the wool with her, and... so yeah, and all the sheets that were filled in, he filled those in for her. But she did it all, she was doing all the activity (Facilitator 1)*

However, one facilitator explained how they had had to manage a supporter who wanted to take the lead:

The partner will want to take the lead and speak for the person; we had to change it a little bit just to say please could they [person with dementia] go first and express their feelings (Facilitator 3)

Not all people with dementia had active support from their family; this was reported as being due to poor *health of the supporter or limited interested from the wider family.*

'I was not able to reach him [the son], so I do not know how aware he was of what we were trying to achieve.' (Facilitator 1)

Relevance of the PRIDE intervention

PRIDE was aimed at those with mild dementia and all thought the intervention would be most useful soon after diagnosis. This supporter explained it helped to reduce fear following a diagnosis:

We wouldn't have known where to go and that actually you can have some sort of life, because when something like that is said to you, you think that's the end. That's actually where the fear comes because really don't know where to turn or what to do and somebody coming in and talking to you about it and helping with these sort of things gives you a vision. (Supporter 4)

I think it's good just being diagnosed because it gives you a look into what help you can get and things like that (Person with dementia 2)

A facilitator confirmed that the PRIDE intervention would give hope to those newly diagnosed with dementia:

I feel that they're trying to recognize somebody that's newly diagnosed, to actually state that because you have a diagnosis, it doesn't mean that life stops. (Facilitator 3)

This contrasted with other dyads where the person had been living with dementia over 12 months. Here facilitators found it most challenging when they were delivering the intervention to 'socially active' couples, who were already very engaged and active in the community. However, it was also recognized that PRIDE may be suitable to lay the foundations of skills that may be useful as dementia progresses:

Because I do think the lady maybe she is at risk of maybe losing some of those activities (Facilitator 3).

The intervention delivery was centred on the PRIDE manual. While the majority found the manual easy to use there were some negative comments on layout and the use of smiley faces:

If you don't mind me saying, I think this is a kiddie's way of doing this. (Person with dementia 3).

The facilitators used the manual in every session. However, they all gave examples of how they had had to adapt delivery; often this was due to over enthusiasm:

On one occasion I had to scrap everything and pull it right back, because we thought too big, it is good experience (Facilitator 1).

Discussion

Overall, the intervention and training was feasible to deliver and was well received by those who took part. Of those eligible 59% consented to be in the study. Seventy-nine percent attended at least two sessions, and 73% attended all three. Setting up sites to be ready to

provide the intervention had its challenges. This study demonstrates that to conduct a future pragmatic randomised controlled trial (RCT) of this type, contextual changes associated with delivery of high quality research and within study-site organisations, should be anticipated with timely ongoing measures taken to overcome challenges. The strength of this study is that: (i) we have good data on the required (albeit lengthy) time to recruit participants; (ii) more study sites would be required to allow for drop-out due to within-organisation changes; (iii) intervention delivery is best developed and organised by the recruiting study-site, since when research teams attempt collaboration across agencies, fluctuating commissioning arrangements can undermine the progress of applied research such as this; (iv) some outcome measures such as the *TUG test* may not be flexible enough for this type of study but overall the instruments were feasible and acceptable to participants when delivered by trained researchers, although all may not be needed in a future large scale-trial .

Recruiting sites as well as participants, is one of the common challenges of health research, but also the key to their success (Borschmann et al., 2014; Kaur, Smyth and Williamson, 2012; Nuno et al., 2017). Estimating adequate recruitment timelines for a large trial is one of the key functions of a feasibility study (Thabane et al., 2010). We found two significant obstacles. The changes in the UK's NHS governance approval system was beyond the team's control and unexpected, especially as we had completed a similar procedure some months prior. Secondly, matching available intervention facilitators to research sites was difficult. The feasibility study required the recruitment of sites that not only had the capacity to identify, recruit and assess participants, but to also have available suitably qualified staff to provide the intervention. Initially, it was envisaged that Dementia Advisors from voluntary organisations would be able to fulfil this role, since at the time there was a policy-driven role in England, in this sector for this type of work. Although the project had the support of the head and regional offices of voluntary organisations, we found that it was untenable to rely

solely on the voluntary sector, since commissioning arrangements varied, in terms of length of contracts and funding for staff. Attrition due to organisational factors and delays in participants recruitment have been found in other studies relying on interventions being delivered by the voluntary sector (Mountain et al., 2017) and although our intervention facilitators were paid employees, similar issues arose. Therefore, NHS staff working with memory clinics, typically nursing staff and clinical graduate dementia advisors were approached to facilitate the intervention. This observation suggests that a wide variety of staff can deliver an intervention of this type. Earlier in the project, the research team had tried facilitating collaboration between NHS sites and the voluntary sector, but stepping back and leaving the study-site to arrange delivery, proved a better strategy. We found that research and treatment resources can fluctuate within NHS research departments, depending on studies supported at a given time and annual allocation of NIHR funding. This resulted in loss of two of six study sites, thus limiting us to predominantly urban locations. A future large-scale study can anticipate potential fluctuations of resource within organisations, and consider stratification of sites according to knowledge of contextual factors, in order to ensure evaluation of the range and diversity of the population studied. Furthermore, we have now developed more specific site-requirements when engaging sites where minimum numbers of both researchers and intervention facilitators, and a commitment to recruit minimum participants per site are scoped in advance (Shafayat et al 2019). Ellwood and colleagues (2018) also found that a targeted approach to site recruitment (in their case, care homes) was more successful and less time-consuming than a broad approach.

Fewer participants than anticipated were recruited, due to the difficulties encountered with site and intervention facilitator recruitment start dates. Our strategy was to continue until we had enough information to guide us when planning a large trial. In calculating participant

numbers for a future large scale study, an opt-out criterion of about one third could be anticipated given that 29% of those who met inclusion criteria opted not to take part. Recruitment via the JDR register was not successful for the following reasons: some potential participants were not adequately aligned to the research site locations, and many did not respond to our attempts to engage them. Recruiting from memory clinics was the most successful method of recruitment. Ill-health was a common cause for not continuing with the study, which given the age of participants is to be expected, but should not be a reason for excluding participants from trials. Of those who remained in the study, compliance with the three intervention sessions was high.

All measures were acceptable to participants apart from some challenges encountered with The *TUG* test; and missing data was minimal (i.e. less than 2%). As with other studies of this type, assessment periods were moderately lengthy (1-2 hours), but all assessments were completed in one visit and no participants were distressed by the questions. With this limited sample, differences between groups were not expected, and were perused for exploratory purposes. Based on the results here, the authors conclude that most of these instruments would be suitable for a large-scale intervention trial, but the burden of applying these can be reduced by using fewer instruments, particularly where underlying concepts overlap. this study provides additional information on the feasibility of using the instruments we chose. These may be considered for other research designs, such as those that aim to elucidate the mechanism of change of psychosocial interventions. Two measures show potential as primary outcome measures, namely the *SMAS-30; Schuurman et al., 2005*); people with dementia and the *EQ-5D; Euroqol Group, 1990)* for supporters.

Participant and facilitator qualitative perceptions of the PRIDE intervention

The convenience sample was small representing only twenty-four per cent of the dyads recruited, but there was consistency in the accounts provided. It was intended to run groups of up to 5 dyads with a mix of gender but staggered recruitment to the intervention meant that several dyads had completed the programme some weeks before the others. All found the intervention acceptable and reported positive experiences. The timing of the intervention is an important factor with most relevance being with those newly diagnosed. Supporters and facilitators encouraged the person with dementia to act and reflect on activities and tasks. Having a facilitator seems to have empowered the person with dementia to be actively involved in the intervention. This maximised the ethos of the PRIDE study and contrasts with previous research where there have been reports of family members trying to do more than is necessary or needed, for or on behalf of, the person with dementia (Sterin, 2002).

Limitations

The main limitation to this study is that we were unable within our timescale to engage the range of sites planned to explore geographical and participant variability. The present study demonstrated that a variety of dementia staff of differing grades and training can successfully deliver this intervention. Research sites were asked to provide details on the time taken to deliver the interventions, such as travel expenses for each of the home visits and administrative (note keeping) time. However, the cost of training and time taken to deliver the intervention could not be accurately calculated as not all intervention facilitators complied. Improved training and more formal regular ongoing communication between the research team and research site-collaborators is required to collect this data. Having only men with dementia in the focus groups is a limitation as social activities can be gendered.

However, age also impacts on social activities and within the sample we had a younger man who was engaging, independently of his supporter, in physical social activities outside of the home. Future work will explore these limitations.

Clinical and Research Implications

Looking further into the mean differences in self-management (*SMAS*) scores, the moderate effect size suggests that with a larger sample significant differences are possible. These findings suggest that not only might the intervention be beneficial in improving self-management, but also that this could be especially true for those who would gain the most benefit from the intervention. Self-management skills, as measured by the *SMAS-30*; (Schuurman et al., 2005), and the confidence to use these skills can be a key asset to limit the excess disability often found to have a significant impact on dementia (Brody et al., 1971; Spector and Orrell, 2010). Given the concept of the PRIDE intervention and its potential for empowering people with mild dementia to live well, these preliminary findings suggest that the *SMAS-30* self-management instrument has good potential as a primary outcome measure in a future large scale trial.

Conclusions

The PRIDE intervention was feasible to carry out and acceptable to persons with dementia and their supporters. Participants engaged with the intervention and reported positive experiences, suggesting that a move to a larger trial is worthwhile. However, recruiting sites with resources and clinical staff to implement the intervention was an unanticipated challenge that impacted on the number and diversity of sites and participants recruited. Our findings do however provide realistic information on recruitment and retention rates,

suggesting longer timelines for site and participant recruitment since for 34 dyads across four urban sites we required 10 months, and suggestions for overcoming the challenges encountered. Involving memory clinic staff as intervention facilitators had a positive impact on overcoming some of the delays encountered. Examination of the performance of outcome measures suggests that most were acceptable and feasible to use. The self-management instrument shows the strongest promise and is in line with the concepts underlying PRIDE. The findings of this feasibility study can be used to inform a future large scale randomised controlled trial of the PRIDE intervention. Some instruments can be omitted from a future psychosocial intervention study particularly where underlying concepts overlap. However, this study provides additional information on the feasibility of using instruments that may be considered in other designs, such as those that aim to elucidate the mechanism of change of psychosocial intervention research.

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Authors' contributions
MO, EMC, GC, EH, and GM developed the original concept of the study. All authors drafted the original protocol, developed the design and methodology and contributed to the development of the PRIDE intervention and manual. EC drafted the paper and is the main author. All authors reviewed and commented on drafts of this paper. All authors read and approved the final manuscript.

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https://www.institutemh.org.uk/research/projects-and-studies/current-studies/protect/246-the-pride-study

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Table 1 Topic guide for focus groups with participants and supporters

Stem Questions and Prompts
1) What did you think of the PRIDE manual? Is there anything you like about the manual? Why? Is there anything you dislike about the manual? Why? Which topics did you choose to work on? Why? Were any of the sections / topics in the manual particularly useful to you? Why? Were any of the sections / topics in the manual ***not*** useful or relevant to you? Why? What do you think about the resources provided for the topics you chose?
2) What did you think of the following exercise? PRIDE profile: information about you (p6-7) Finding a balance grid (p8) People and connections bubbles (p12) People and connections support network map (p14) Making decisions: How do you make decisions? (p42) Getting your message across: Supportive relationships (p58) Do you have any suggested changes for these exercises?
3) What did you think of the clarity of information/language used/layout and design? How well were you able to follow the manual? (eg finding the right page) Were you able to understand the information presented in the manual? (eg appropriate language used, non academic terms) What do you think about the layout of information? (eg any issues with clarity, size of text, presentation of information?) What do you think of the design of the manual? (eg color, images)
4) What do you think about the intervention/programme? Was the programme useful? (eg If yes, in what ways? If no, why not? How could the programme have been more helpful for you?) Did you make any changes to your activities/lifestyle/actions related to taking part in this programme? If so, what changes did you make? Why? If not, why not? How was your experience of working with a dementia advisor? Was three sessions too many, too few, or just right for this programme? How long did your sessions tend to take? Was this too long, too short, or just right? (If too long or short – recommend a suitable amount of time)
5) What did you think of the plan, do, review section? Did you find planning activities and actions helped you to actually go and do them? How did you find keeping track of your activities/actions? (eg Useful? Time-consuming?) What do you think about reviewing your activities/actions in sessions 2 & 3 with your advice worker? (eg Useful? Meaningful?) What do you think about the worksheets?
6) Did you use support? Did you need any support to do the programme? (eg, How often? What kinds of support?)

Were you satisfied with the support you received while you were taking part in the intervention?
7) Did you experience any challenges? Did you have any problems with the programme? If so, how did you overcome these?
8) Experience of PRIDE. Thinking about your experience on this project, what went well? Was there anything that didn't go so well? (eg anything you were not satisfied with)

Table 2. Topic guide for intervention facilitators who delivered the PRIDE Intervention.

Stem Questions and Prompts
1) Please can you tell me about your experience of working with people with dementia?
2) How have you found the experience of delivering the PRIDE intervention? - How difficult or easy is it to deliver the intervention? - Why?
3) How helpful was the training in enabling you to deliver the PRIDE intervention? - What was most helpful? - What was least helpful?
4) Now that you have delivered the intervention is there anything you would change about the training? - Manual - Content - Style of delivery
5) **How did you make contact with participants prior to starting the intervention?** - Who gave you information? - What about type of information you had about participants? - How long between getting information and starting intervention? - Where there any barriers to starting the intervention
6) To what degree were the skills and knowledge taught in training useful for delivering the Intervention? - Practical skill? - Theoretical knowledge ?
7) Did you use the DAW training manual alongside the PRIDE manual? - If so, did how did this work? - If not, why not?
8) **Which parts of the DAW training manual are most useful when delivering intervention session**
9) Which part of the DAW training manual might need to change? - If so, what changes would you make? Eg omitting content (and what?), adding content (and what?)
10) Have you experienced any barriers to applying what you learned in training to the Intervention? - Resource - Understanding - Links between training and intervention delivery
11) For you, what was the most important part of the intervention? - Why was that most important?

12) For you, what was the least helpful or important part of delivering the intervention, and why?

- Why was that least helpful or important in your view?
- How would you change it?

13) Which part of the intervention do you think participants most benefited from, and why?

- In what ways did they benefit?
- Did participants report benefits or is this based on your observations?

14) Which part of the intervention do you think participants least benefited from and why?

- In what way?

15) What did you think of the PRIDE manual?

- Was the language easy to understand?
- How easy was it to navigate between sections?
- What did you think of the case stories?

16) What did you think of the additional resources? For example the 'do' and the 'review' worksheet?

- How did you use them?
- What, if anything, would you change?

17) How do you feel about your ability to deliver the intervention?

- What would help you feel more confident about your ability to deliver PRIDE as planned?

18) **How do you feel about the time you had to deliver the Intervention?**

- Where there other time constraints?
- Did participants need/use three sessions?

19) Would you recommend others do the DAW training?

- If yes, why and what specifics?
- If no , why and what specifics?

20) What strategies did you use to deliver the PRIDE intervention?

- Use of DAW manual
- Use of PRIDE manual
- Training in delivery of intervention
- Support from PRIDE team
- Support from colleagues
- Other things

21) Is there anything else that you would like to say about the issues we have talked about?

Table 3: Persons with dementia baseline (BL) and follow up (FU) scores

	Baseline (N=34)	Follow Up (N=27)
Questionnaire	**Mean (SD)**	**Mean (SD)**
Engagement and Independence in Dementia Questionnaire (EID-Q)	81.40 (15.89)	83.74 (12.42)
Control, autonomy, pleasure, and self-realization (CASP 19)	23.22 (6.07)	22.70 (5.56)
Impact on Participation and Autonomy (IPA)	6.95 (3.06)	6.67 (3.44)
Positive Psychology Outcome Measure (PPOM)	49.51 (9.30)	50.81 (50.81)
Self Management Abilities Scale 30 (SMAS 30)	91.94 (17.17)	98.19 (13.55)
ICECAP-O*	15.24 (2.40)	15.96 (2.27)
EQ5-D (Health related quality of life)	.80 (.23)	.81 (.23)
EQ5-D VAS	70.97 (18.50)	74.56 (18.82)
Timed Get up and Go (TUG)	15.17 (6.04)	13.60 (8.29)
Hopkins Verbal Fluency and Learning Test (HVLT) Total	11.09 (4.60)	12.34 (5.2)
Dementia Quality of Life (DEMQOL) Total	91.56 (13.21)	91.85 (16.37)
Standardized Mini-Mental State Examination (SMMSE)	23.97 (4.24)	22.85 (5.61)
ELSA: ELSA self-perceived social connectedness	5.65 (1.43)	5.68 (1.21)
The Bristol Activities of Daily Living Scale (BADLS) *	13.03 (7.86)	11.75 (8.02)
(Dementia Quality of Life (DEMQOL) Total *	95.53 (10.78)	96.23 (11.12)
EQ5-D Proxy*	.65 (.23)	.69 (.20)
EQ5-D VAS Proxy *	63.38 (18.05)	64.92 (17.15)

High scores indicate better well-being except on the IPA, EQ5-D and ELSA. * Note. N=26

Table 4: Supporters baseline (BL) and follow up (FU) scores

	Baseline (N=34)	Follow Up (N=26)	T-
Questionnaire	**Mean (SD)**	**Mean (SD)**	
ICECAP-O	13.47 (3.06)	14.54 (3.29)	
EQ5-D	.74 (.24)	.78 (.22)	
EQ5-D VAS	76.35 (13.58)	81.46 (11.64)	

Note. High scores on ICECAP-O scores indicate greater wellbeing, high scores on EQ5D indicate lower wellbeing.

Table 5. Enactment of the PRIDE intervention and SMAS scores. Post hoc exploration.

	Mean SMAS	
	Baseline	Follow up
Self -reported Enactment Time 2*		
76-100% enactment	97.64 (SD 15.60; n=10)	97.70 (SD 10.43; n=10)
≤75% enactment	78.61 (SD 16.28; n =9)	96.42 (SD 12.87; n= 9)
Self -reported Enactment Time 3		
76-100%	97.58 (SD 18.73; n= 9)	94.90 (SD 16.03; n = 9)
≤75%	77.50 (SD 21.00; n= 5)	96.35 (SD 13.82; n=5)
Unknown	92.94 (SD 16.07; n=11)	104.50 (SD 9.95; n=4)

*Enactment was measured after interventions sessions 2 and 3 only.

Note. N's in the unknown group are those who did not complete either the T2 or T3 enactment question

(For more details on the overall engagement scores see Walton et al, 2018[23]).